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Project Title: MS Persons and Computers

Investigator(s): Virginia R. Griffin

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ABSTRACT

For large-scale projects, please provide in the space below an abstract of not more than 300 words, single-spaced, written in a language that may be understood by the informed layperson. For small-scale projects, an abstract per se may not be appropriate, and the report itself may be started below.

REPORT ATTACHED

## MS PERSONS AND COMPUTERS

### PURPOSE OF STUDY

The purpose for this study was to learn more about the state of the use of computers by one important group of people who could benefit greatly from the use of computers: those who have multiple sclerosis. This increased knowledge could serve three purposes:

a) aid in helping adult educators who want to be involved in a technologically and personally relevant project understand what the needs are with this one group of disabled, semi-disabled and able-bodied people, and how adult educators can make a contribution.

b) give me a base for determining what future research is needed in this area, and a base of experience to decide if I have the physical and emotional stamina to continue this line of research.

c) help me learn ways others with MS are using computers to cope with having the disease so that I can learn better to use present-day technology to help me make fullest use of my capabilities, given the limitations I have because of the disease.

d) provide the MS Society with information for their program of assistance for persons with MS.

### METHODOLOGY / APPROACH

The approach taken was a heuristic, qualitative one. I kept a 12 month learning journal of my experience of buying a computer and related equipment, learning to operate it, and using it. From my journal I identified major issues in my experience that I wanted to explore further with others. I then identified seven other people who have MS and use computers in order to interview them about their experience with the issues I had identified plus any others relevant to them.

The people were located by means of an announcement at the York East chapter of the MS Society, an announcement in their newsletter; seeking names from staff members of the MS Society; contacting other agencies such as Alternative Computer Training, Designing Aides for Disabled Adults, York Region Vocational Rehabilitation Service, the MS Clinic at St. Michael's Hospital; and asking friends, a local pharmacist, and students in our program. Some of these contacts were non-productive, especially in identifying women who met the criteria. Further leads could have been pursued to locate women, but were not because of lack of time. It is interesting that it has been difficult to find women (other than those who live in hospitals, who could have been interviewed

only after an involved hospital ethical review process) because MS is more commonly a disease of women than it is of men. It will be useful to explore whether there is a widespread phenomenon that women with MS are less likely to have and use a computer than are men with MS.

Some of the persons interviewed were active in the MS Society, others were not. Most lived in Toronto, others lived in rural areas or small towns north of Toronto.

Some of the issues I identified were common issues for all, although the ways persons experienced these issues differed. Some issues relevant for me were not relevant for others. One issue emerged which had not occurred to me, but is reported here.

#### **LEVEL OF DISABILITY AND ASSOCIATED USES AND MEANINGS**

The eight people (myself included) can be divided into three groups, based on a combination of level of disability and ability to be employed. The use made of computers, features of the computer, and the meaning of the computer differ for each of these groups. These three groupings have immense implications for educational, service, and research programs. These groups are (A) mobile and employed, (B) mobile and retired (disability) and (C) immobile and working. (My study did not include any immobile, retired [disability] persons.)

**(A) Mobile and Employed** This was the largest group--4 people. They are all mobile, although several sometimes use canes or a scooter. They all experience limitations, especially fatigue, and poor balance. One is presently unemployed, but looking for a job, having just completed a year's course at ACT. One is using her computer primarily to write a book related to her career specialty, with minimal personal use for the computer. Personal benefits do accrue (time for self and family). One uses his computer for nearly all of his work (editing and sending newsletters, writing manuscripts, writing business letters etc.); he uses his computer some for personal purposes (letters, intellectual games, interactions with his daughter). But the important meaning for him is that using the computer allows him to work, and has helped him settle into a career. The fourth person also has found that the computer allows her to continue to work, and also do personal things because hand writing is so difficult, and her typewriting has become so poor. Journal keeping and using the computer has led to increased self-understanding. All reported the ease of producing work (word processing primarily) with a computer as one of the main advantages of the computer to them (perhaps because of the fatigue factor).

The women all claimed that the emotional benefits of having learned to

use the computer: self-esteem, confidence, being up-to-date, instead of behind the times, and on a par with colleagues to be as important as the work they can now do.

**(B) Mobile and Retired (disability)** Two men were in this group. They had had MS longer than others, and had had their computers longer than did others. They are on disability retirement, having been in jobs that required much driving and moving about. Both have difficulty walking, but drive cars for personal use. The use they make of their computers is primarily for recreation: chess and other assorted challenging games. Of secondary importance to them is their use of their computers for social action activities on behalf of other MS persons. One of the men, who had been a truck driver, seems to have a redefined purpose in life: to find ways he can use his computer in order to be of help to others.

An issue that emerged here is the impact of government and insurance company policies on disability retirement. It operates as a disincentive for people to use computers in order to be employed at part-time work (which is often the most an MS person can do) because disability retirement is "all-or-none" and for "permanent" disability situations. (Those with exacerbating/remitting MS can work at times and at other times not and need "sporadic" disability options. Some think this factor is a critical reason that more MS persons do not have computers.

**(C) Immobile and Working** I felt very privileged to meet two courageous men who are wheelchair bound and have other serious disabilities and who have found ways to use computers for gainful employment. One is a CA working for a company part-time. What he can't finish at work on his computer there, he brings home to finish on his home computer, transfers it to a floppy disk and takes it back to work. He has a six power magnifying lens that attaches to his glasses which allows him to see the computer screen. He also uses his home computer to do social action committee work. The other man is unable to use his arms and his legs. The adaptation he has selected for his computer is a "sip and puff" mouthpiece, which has necessitated his learning the Morse code. He has a program which will open the door, dial the phone, and other wondrous things as soon as DADA can find a computer-literate volunteer to help him learn how to use the program. He has the disadvantage of not being able to hold a manual or turn the pages to teach himself. He finds that his computer allows him to express himself, keep records, function in daily chores, do many ordinary things that normal people take for granted, but make a great difference to him. He and a

partner have formed a business to develop architecture and construction projects.

**Summary of Uses and Meanings** The above paragraphs reveal that the computer does serve the purpose most of the literature about the disabled suggest it can: it helps disabled people be employed in useful work. However, there are additional meanings that a computer does have. Emotional impact (self-esteem, confidence), recreation and productive use of time when retired, (however the individual defines "productive"), substituting for bodily functions that no longer work (e.g. handwriting or arm movement,) saving energy for other goals in life, redefinition of life purpose, and increased self-understanding are all worthy goals for which a disabled person might find a computer useful. Literature for disabled persons could make more of these goals to encourage more people to acquire and use a computer.

In short, persons interviewed often feel that having MS has transformed their lives. Having a computer has not necessarily transformed their lives, but it has **enriched** each person's life.

#### **PROBLEMS AND HELP NEEDED**

**Modems** A modem seems like a logical piece of equipment for a person who has difficulty moving about or who has problems with fatigue. Only three of these persons have modems, and none use them, or are comfortable that they know how to use them. Only one (me) had heard of the DISC program (Disabled Information Services of Canada), a program established by funds from the Secretary of State. There are very few data banks or bulletin boards available in Canada, what are there are not well known. Some means needs to be found to help disabled people learn how to use a modem once useful data banks are created. Possibilities for disabled people who live outside the 20-some Datapak cities in Ontario, to use their modems without long distance charges, should be found or created. Those who are on reduced income find the thought of having a modem prohibitively expensive. Connecting to U.S. data banks is also prohibitively costly.

Several mentioned plans to acquire and use **facsimile machines** as a useful alternative technology, especially those whose offices have that facility, allowing greater freedom of work from "home".

**Deciding What to Buy.** Becoming aware of what is available, pros and cons of each brand or model, costs, how each would fit with one's capabilities and intended uses are types of information few MS persons have energy or time to

explore. Books available on this topic are quickly out of date, and based on makes and models available in the States. DADA might help on this problem, but is primarily designed to help persons needing special adaptations such as the two severely disabled persons in my study. Others of us were left to seek help from friends, family or friends who work at IBM, or computer experts at work. There is not a person available to most who can give a fair and honest appraisal of available equipment, and help us fit it to what we need. Such a consumer resource needs to be made available.

**Disability Pension Policies** The need for new attitudes and policies on the part of government and insurance companies was described above.

**Honoring the Specialness of Every Adult** Every adult, even disabled ones with visible or invisible disabilities, wants to feel in control of his/her own life, and allowed to make his/her own choices. Persons giving problems in this area to those interviewed were a course instructor or a friend tutoring who taught more than the student wanted to know (making him feel inadequate), and persons giving advise on adaptations for computers.

Although three of the people in this study were grateful recipients of financial assistance with their computer purchase, from the Vocational Rehabilitation Service, one found the process of applying for the aid so demanding for his level of capability, the stress almost resulted in his being hospitalized. Undue stress is a problem for persons with MS, and any person dealing with us should learn to make their rules and regulations as humane as possible, and help us find ways to comply that are within our capabilities.

**Clearer Instructions; Instructions on Tape for the Visually Impaired** A common problem was difficulty in understanding (even reading) manuals that accompany software programs and modems. They often assume you know something you haven't yet been exposed to, causing hours of problem solving and wasted time when one's purpose is to save time and energy. and reduce stress in one's life. One woman recently found a very clear book dealing with solving problems with the Word Perfect program. She said it made things very clear, and if she had had it when she first bought the program, she could have saved hours and hours of frustration.

A need mentioned by one person who is visually impaired is to have manual instructions available on audio tape.

**LEARNING PROCESSES AND PHASES** Learning to use the computer involved a mix of studying magazines and manuals, trial and error, figuring it out for yourself, playing with the possibilities, consulting with friends or colleagues, taking a course (year-long or short). Several were apologetic about their playing to learn, trial and error exploration. All need to be made aware that there is no one right ways to learn, and to value their own processes. The phases described all ended with the sentiment: but I know it can do more than I have asked it to. There is more that I can learn to do with it. One man used the metaphor: I feel like I have a Mercedes, but I can drive it only in low gear.

**METAPHORS USED IN THINKING ABOUT COMPUTERS** In addition to the Mercedes metaphor above, other metaphors are used. Some thought of "the machine", some "a useful tool", but others had named their computer or called it unpleasant names when it was "misbehaving". Although all knew it was an inanimate thing that did only what you "instructed" it to do, most had a personal relationship with it, talked to it, and blamed it when it wouldn't do what they wanted it to. This contrasted with the early stage of feeling awe for what it could do.

**IMPLICATIONS FOR ME** One of the purposes of the study had to do with my future research and my use of computer technology in coping with my MS. I feel able to do more of this kind of research with disabled people. But after studying even these few people, I am convinced field development work is called for, more than research, unless research with a larger population (province-wide, or national) would make the field service goals more saleable.

A major outcome for me was discovering how much the acquiring and using of a computer is a social activity, rather than a lonely, isolating one. It seemed so for others in my study, too. Hours are spent alone with a computer, but interaction with others about problem-solving, shared experiences, self-understanding, functioning as well as an able-bodied person, and the wonders of an enriched life more than compensate for any isolation? I also sensed an unusual kind of camaraderie with the persons with whom I shared this project, and I remain grateful to them.